ID Number:

UKOSS

UK Obstetric Surveillance System

Pulmonary vascular disease
Study 01/06

Data Collection Form - CASE

Please report any woman who delivered after 1st March 2006.

Case Definition:

EITHER Pulmonary hypertension defined as:

1) a mean (not systolic) pulmonary artery pressure equal to or greater than 25mmHg at rest or 30 mmHg on exercise in the absence of a left-to-right shunt

OR

2) a pulmonary artery systolic pressure greater than 36mmHg. Pulmonary hypertension may be primary (no cause identified) or secondary (known cause identified, for example, vasculitis, connective tissue disease, chronic pulmonary thromboembolism, sickle cell disease, drug use)

OR Eisenmenger's syndrome: defined as pulmonary hypertension secondary to an uncorrected left-to-right shunt from a ventricular septal defect, atrial septal defect or patent ductus arteriosus.

Please note: Pulmonary arterial pressures measured by Doppler will be mean values. Systolic pressures can be measured by pulmonary artery catheter.

Please return the completed form to:

UKOSS
National Perinatal Epidemiology Unit
University of Oxford
Old Road Campus
Oxford
OX3 7LF
Fax: 01865 617775
Phone: 01865 289714

Case reported in: _____

Royal College of Obstetricians and Gynaecologists

npeu National Perinatal Epidemiology Unit

Instructions

1. Please do not enter any personally identifiable information (e.g. name, address or hospital number) on this form.

2. Please record the ID number from the front of this form against the woman's name on the Clinician's Section of the blue card retained in the UKOSS folder.

3. Fill in the form using the information available in the woman's case notes.

4. Tick the boxes as appropriate. If you require any additional space to answer a question please use the space provided in section 7.

5. Please complete all dates in the format DD/MM/YY, and all times using the 24hr clock e.g. 18:37

6. If codes or examples are required, some lists (not exhaustive) are included on the back page of the form.

7. If the woman has not yet delivered, please complete the form as far as you are able, excluding delivery and outcome information, and return to the UKOSS Administrator. We will send these sections again for you to complete two weeks after the woman's expected date of delivery.

8. **If you do not know the answers to some questions, please indicate this in section 7.**

9. If you encounter any problems with completing the form please contact the UKOSS Administrator or use the space in section 7 to describe the problem.

Section 1: Woman's details

1.1 Year of birth Y Y Y Y

1.2 Ethnic group[1]* *(enter code, please see back cover for guidance)* ☐☐

1.3 Marital status single ☐ married ☐ cohabiting ☐

1.4 Was the woman in paid employment at booking? Yes ☐ No ☐

If Yes, what is her occupation _____

If No, what is her partner's (if any) occupation _____

1.5 Height at booking ☐☐☐ cm

1.6 Weight at booking ☐☐☐.☐ kg

1.7 Smoking status never ☐ gave up prior to pregnancy ☐ current ☐ gave up during pregnancy ☐

*For guidance please see back cover

Section 2: Previous Pregnancies

2.1 Gravidity

Number of completed pregnancies beyond 24 weeks ☐☐

Number of pregnancies less than 24 weeks ☐☐

If no previous pregnancies, *please go to section 3*

2.2 Did the woman have any previous pregnancy problems?[2]* Yes ☐ No ☐

If Yes, please specify _____

Section 3: Previous Medical History

Please indicate whether any of the following were present prior to pregnancy:

3.1 Previous or pre-existing medical problems[3]* Yes ☐ No ☐

If Yes, please specify _____

3.2 Eisenmenger's syndrome Yes ☐ No ☐

If Yes, please specify date of diagnosis D D / M M / Y Y

and underlying cause _____

3.3 Pulmonary hypertension Yes ☐ No ☐

If Yes, please specify date of diagnosis D D / M M / Y Y

If Yes, was any cause for pulmonary hypertension diagnosed?[4]* Yes ☐ No ☐

If Yes, please specify _____

3.4 Was pulmonary artery pressure measured prior to pregnancy? Yes ☐ No ☐

If Yes, please record the highest mean arterial pressure at rest (mmHg) ☐☐☐

During exercise (mmHg) ☐☐☐

3.5 Most recent arterial oxygen saturation prior to pregnancy

Rest: ☐☐ % Exercise: ☐☐ % **Or** tick if neither known ☐

3.6 Was pre-pregnancy counselling given? Yes ☐ No ☐ Not documented ☐

Section 4:

Section 4a: This Pregnancy

4a.1 Final Estimated Date of Delivery (EDD)[5]* D D / M M / Y Y

4a.2 Was care undertaken in the usual hospital for this woman's area of residence?

Yes ☐ No ☐

Name of usual hospital of residence _____

If No, please indicate below reasons for care at a different hospital *(please tick all that apply)*

Referred to a tertiary centre because of underlying medical condition ☐

Patient preference ☐

Other ☐

If Other, please specify _____

*For guidance please see back cover

4a.3 Was this pregnancy a multiple pregnancy? Yes ☐ No ☐

If Yes, specify number of fetuses ☐

4a.4 Were there problems in this pregnancy[2]* Yes ☐ No ☐

If Yes, please specify _____

Section 4b: Course of Disease

4b.1 Was the diagnosis of Eisenmenger's/pulmonary hypertension first made during this pregnancy? Yes ☐ No ☐

If Yes, please specify diagnosis _____

and date of diagnosis D D / M M / Y Y

4b.2 Was a recording of pulmonary artery pressure made during this pregnancy? Yes ☐ No ☐

If Yes, was it Doppler-derived ☐ catheter-derived ☐

Please record highest measured pulmonary arterial pressure ☐☐☐

4b.3 Was the lowest arterial saturation recorded pre-labour/delivery? Yes ☐ No ☐

If Yes, Date of recording D D / M M / Y Y Rest: ☐☐ % Exercise: ☐☐ %

4b.4 Please record all hospital admissions during this pregnancy, that included at least one overnight stay. *Please continue in section 7 if necessary*

Date of admission	Date of discharge	Reason for admission and any complications during admission	Was the woman delivered during this episode?
			Yes ☐ No ☐
			Yes ☐ No ☐
			Yes ☐ No ☐
			Yes ☐ No ☐

4b.5 Please indicate which of the following specialists were involved in the care of the woman during pregnancy

			Date first consulted
Cardiologist	Yes ☐	No ☐	D D / M M / Y Y
Fetal-maternal medicine specialist	Yes ☐	No ☐	D D / M M / Y Y
Obstetric anaesthetist	Yes ☐	No ☐	D D / M M / Y Y
Obstetric physician	Yes ☐	No ☐	D D / M M / Y Y
Other	Yes ☐	No ☐	D D / M M / Y Y

If Other, please specify _____

*For guidance please see back cover

Section 4c: Therapy for pulmonary vascular disease

4c.1 Please specify if any of the following therapies were used *(please tick all that apply)*:

		Prior to pregnancy	During pregnancy
Aspirin		☐	☐
Theraputic anticoagulation	- Warfarin	☐	☐
	- Heparin	☐	☐
Prophylactic anticoagulation	- Warfarin	☐	☐
	- Heparin	☐	☐
Calcium antagonists		☐	☐
Endothelin antagonists (Bosentan)		☐	☐
Iloprost		☐	☐
Magnesium sulphate		☐	☐
Nitrates		☐	☐
Nitric Oxide		☐	☐
Phosphodiesterase inhibitors (Sildenafil)		☐	☐
Prostacyclin (PGI2) (Epoprostenol)		☐	☐
Other		☐	☐

If Other, please specify _____

Section 5: Delivery

5.1 Did this woman have a miscarriage? Yes ☐ No ☐

If Yes, please specify date D D / M M / Y Y

5.2 Did this woman have a termination of pregnancy? Medical ☐ Surgical ☐ No ☐

If Yes, please specify date D D / M M / Y Y

5.3 Is this woman still undelivered? Yes ☐ No ☐

If Yes, will she be receiving the rest of her antenatal care from the current hospital? Yes ☐ No ☐

If care is to be provided at a different hospital, please indicate name of hospital providing future care, *then go to section 7* _____

If No, please continue

5.4 What was the planned mode of delivery? vaginal ☐ caesarean section ☐

5.5 What was the NYHA grade of disease severity at delivery[6]*? ☐

*For guidance please see back cover

5.6 Was delivery induced? Yes ☐ No ☐

If Yes, please state indication _____

Was vaginal prostaglandin used? Yes ☐ No ☐

5.7 Did the woman labour? Yes ☐ No ☐

If Yes, was labour augmented with syntocinon? Yes ☐ No ☐

What was the method of analgesia for labour *(please tick all that apply)*

Entonox ☐ Opiate ☐ specify: im, iv, PCA (please circle)

Regional ☐ specify: epidural, single-shot spinal, continuous spinal, CSE *(please circle)*

Other ☐

If Other, please specify _____

5.8 Was delivery by caesarean section? Yes ☐ No ☐

If Yes, please state whether elective ☐ **OR** emergency ☐

Please state grade of urgency[7]* ☐

and give indication for caesarean section _____

Method of anaesthesia: single-shot spinal ☐ continuous spinal ☐ CSE ☐ general ☐

5.9 Monitoring during delivery *(please tick all that apply)*

non-invasive blood pressure ☐ ECG ☐ central venous pressure (CVP) ☐

intra-arterial blood pressure ☐ pulse oximetry ☐ pulmonary artery pressure ☐

Other ☐

If Other, please specify _____

5.10 Treatment/prevention of uterine atony *(please tick all that apply)*

syntocinon ☐ syntometrine ☐ ergometrine ☐ uterine balloon ☐

B. Lynch suture ☐ Other ☐

If Other, please specify _____

Section 6: Outcomes

Section 6a: Woman

6a.1 Was ITU admission planned prior to delivery? Yes ☐ No ☐

6a.2 Was the woman admitted to: ITU ☐ HDU ☐ obstetric HDU ☐ No ☐

Date of admission D D / M M / Y Y

duration of stay (days) ☐☐

Or Tick if woman is still in ITU/HDU ☐

Or Tick if woman was transferred to another unit (same hospital) or different hospital ☐

6a.3 Did any other major maternal morbidity occur?[8]* Yes ☐ No ☐

If Yes, please specify _____

6a.4 Did the woman die? Yes ☐ No ☐

If Yes, please specify date and time of death D D / M M / Y Y h h : m m (24hr)

What was the primary cause of death as stated on the death certificate?
(please state if not known) _____

*For guidance please see back cover

Section 6b: Infant 1

NB: **If more than one infant**, for each additional infant, please photocopy the infant section of the form *(before filling it in)* and attach extra sheet(s) or download additional forms from the website: www.npeu.ox.ac.uk/ukoss

6b.1 Date and time of delivery D D / M M / Y Y h h : m m (24hr)

6b.2 Mode of delivery

spontaneous vaginal ☐ ventouse ☐ lift-out forceps ☐ rotational forceps ☐

breech ☐ pre-labour caesarean section ☐ caesarean section after onset of labour ☐

6b.3 Birthweight ☐☐☐☐ g

6b.4 Was the infant stillborn? Yes ☐ No ☐

If Yes, *go to section 7*

6b.5 5 min Apgar ☐☐

6b.6 Was the infant admitted to the neonatal unit? Yes ☐ No ☐

If Yes, duration of stay (days) ☐☐

Or Tick if infant is still in NICU/SCBU ☐

Or Tick if infant was transferred to another hospital ☐

6b.7 Did any major infant complications occur?[9]* Yes ☐ No ☐

If Yes, please specify _____

6b.8 Did this infant die? Yes ☐ No ☐

If Yes, please specify date of death D D / M M / Y Y

What was the primary cause of death as stated on the death certificate?
(please state if not known) _____

Section 7:

Please use this space to enter any other information you feel may be important

_____

_____

_____

_____

_____

_____

_____

Section 8:

Name of person completing the form _____

Designation _____

Today's date D D / M M / Y Y

You may find it useful in the case of queries to keep a copy of this form.

*For guidance please see back cover

Definitions

1. UK Census Coding for ethnic group

WHITE
- 01. British
- 02. Irish
- 03. Any other white background

MIXED
- 04. White and black Caribbean
- 05. White and black African
- 06. White and Asian
- 07. Any other mixed background

ASIAN OR ASIAN BRITISH
- 08. Indian
- 09. Pakistani
- 10. Bangladeshi
- 11. Any other Asian background

BLACK OR BLACK BRITISH
- 12. Caribbean
- 13. African
- 14. Any other black background

CHINESE OR OTHER ETHNIC GROUP
- 15. Chinese
- 16. Any other ethnic group

2. Previous or current pregnancy problems, including:

Thrombotic event
Amniotic fluid embolism
Eclampsia
3 or more miscarriages
Preterm birth or mid trimester loss
Neonatal death
Stillbirth
Baby with a major congenital abnormality
Small for gestational age (SGA) infant
Large for gestational age (LGA) infant
Infant requiring intensive care
Puerperal psychosis
Placenta praevia
Gestational diabetes
Significant placental abruption
Post-partum haemorrhage requiring transfusion
Surgical procedure in pregnancy
Hyperemesis requiring admission
Dehydration requiring admission
Ovarian hyperstimulation syndrome
Severe infection e.g. pyelonephritis

3. Previous or pre-existing maternal medical problems, including:

Cardiac disease (congenital or acquired)
Renal disease
Endocrine disorders e.g. hypo or hyperthyroidism
Psychiatric disorders
Haematological disorders e.g. sickle cell disease, diagnosed thrombophilia
Inflammatory disorders e.g. inflammatory bowel disease
Autoimmune diseases
Cancer
HIV

4. Known secondary causes of pulmonary hypertension, including:

Chronic pulmonary thromboembolism
Antiphospholipid syndrome
Connective tissue disorders
Sickle cell disease
Drug misuse

5. Estimated date of delivery (EDD):

Use the best estimate (ultrasound scan or date of last menstrual period) based on a 40 week gestation

6. New York Heart Association classification grades of disease severity:

1. No functional limitation
2. Slight functional limitation (fatigue, palpitations, dyspnoea or angina on ordinary exertion)
3. Marked limitation (symptoms on less than ordinary exertion but not at rest)
4. Inability to perform any physical activity without symptoms (with or without symptoms at rest)

7. RCA/RCOG/CEMACH/CNST Classification for urgency of caesarean section:

1. Immediate threat to life of woman or fetus
2. Maternal or fetal compromise which is not immediately life-threatening
3. Needing early delivery but no maternal or fetal compromise
4. At a time to suit the woman and maternity team

8. Major maternal medical complications, including:

Persistent vegetative state
Cardiac arrest
Cerebrovascular accident
Adult respiratory distress syndrome
Disseminated intravascular coagulopathy
HELLP
Pulmonary oedema
Mendleson's syndrome
Renal failure
Thrombotic event
Septicaemia
Required ventilation
Right heart failure

9. Fetal/infant complications, including:

Respiratory distress syndrome
Intraventricular haemorrhage
Necrotising enterocolitis
Neonatal encephalopathy
Chronic lung disease
Severe jaundice requiring phototherapy
Major congenital anomaly
Severe infection e.g. septicaemia, meningitis
Exchange transfusion